INTER-REGIONAL REVIEW

Supplement Number 1, 1982

The IYDP Lecture

How to make life easier

for

VISUALLY DISABLED PATIENTS

and the people who

look after them

FOREWORD

During the International Year of Disabled People the Southern and Western Regional Association set itself the task of helping visually disabled people in hospitals by giving the staff who nurse them a few elementary hints about looking after blind and partially sighted people. It should, moreover, be borne in mind that many people who manage quite adequately at home do not feel the full effect of their visual impairment until they are being looked after in the unfamiliar setting of a hospital.

A team of speakers gave lectures - each one of an hour's duration - in hospitals to nurses and a variety of ancillary medical personnel, showing a few simple gadgets and techniques designed to make daily living, even in a hospital ward, easier for visually disabled people. These talks were also given to community nurses and nurses in specialist eye hospitals or wards.

The lectures were given free of charge in 119 different hospitals during the year to well over 2,000 people. By local arrangement they continue to be given.

A comment - typical of many - was received by the Regional Association from Barnet General Hospital. The Acting Divisional Nursing Officer (Community) wrote - "Please convey our sincere thanks to Mrs Fenton who gave an excellent talk - we could have listened to her for hours!"

The Regional Association's sincere thanks also are due to Mrs Jean Fenton, the Secretary of the Hertfordshire Society for the Blind, who, with the help of others from among the speakers, has distilled the essence of those IYDP lectures in this publication which we hope may be of continuing help to health personnel in enabling them to make life easier for visually disabled people.

John A. Wall

airman, Inter-Regional Committee

VISUALLY DISABLED PATIENTS - HOW THEY CAN BE HELPED

This is a sighted world and most hospitals are geared to sighted people. Problems faced by visually handicapped patients are exaggerated by the strangeness of the surroundings and the worries inevitably associated with admission to hospital.

In some cases the patient will be adjusted to his visual handicap before admission, in other cases the patient, who has been coping reasonably well in familiar surroundings, is unaware of the extent of his handicap and may be disorientated in a hospital ward. In a few instances the onset of visual handicap is part of the condition leading to admission and very special care is needed to help the patient to cope with illness, loss of sight and strange surroundings all occurring at the same time.

WHAT IS BLINDNESS?

It is not always appreciated that only 10% of registered blind are totally without sight, the other 90% have varying degrees of useful vision. Unless this is understood there can be considerable confusion when staff find that someone who is said to be blind can actually see. Generally speaking, people are said to be "blind" if they cannot read at 3 metres or less what people with normal sight can read at a distance of 60 metres. In addition to sharpness of vision the field of vision is measured and this means that someone who can see very clearly, but only in a small field, can still be eligible for blind registration. If the patient's sight is not so bad as to make him eligible for blind registration, he may be deemed to have "defective vision of a substantial or permanently handicapping character" and be eligible for partially-sighted registration.

The registration procedure starts with a referral to a Consultant Ophthalmologist who conducts an examination. If the patient's vision is such that he is eligible for registration either as blind or partially-sighted, the Consultant completes Form BD8. The Local Authority which covers the area where the patient normally lives is notified of the recommendation and the patient is then visited by a member of staff from the Social Services Department who informs him of the implications of registration and of the services available. Registration is voluntary, but if a person refuses to have his name placed on the register he may well lose out on such benefits as would otherwise be available to him. Apart from patients who decide not to accept registration, there are a great many more people with defective vision than the statistics would suggest. These people need to have their visual problems taken into account and to be offered the same consideration and help which registered people need in hospital and elsewhere.

EYE CONDITIONS AND THEIR EFFECTS

People who are classified as blind may have macular degeneration which means they have reasonable guiding vision but are unable to focus on detailed work such as sewing or reading. On the other hand, they may have tunnel vision which means they can see very clearly in a small field but have no side vision. Hemianopia, which causes half vision, may leave the patient totally unaware of what he is not seeing on his blind side. Diabetics can have variable eye conditions caused by haemorrhages which occur at intervals and then clear again.

Slides or simulating spectacles which show the effects of various eye conditions can be borrowed from the Southern and Western Regional Association for the Blind. For details see page 16.

Whatever the cause of the visual impairment, the problems arising are as many and varied as the patients

themselves, but they will all have in common a need to be reassured and helped to maintain as much dignity and independence as possible. To achieve this a reliable means of communication should be established from the start.

COMMUNICATION WITH THE VISUALLY HANDICAPPED NEEDS TO BE BY WORDS OR BY TOUCH - OR BY BOTH

A nod or a smile, however cheerful, is not going to mean much to someone who cannot see it. If you expect a response from people with whom eye contact is not possible it is important to address them by name and tell them who you are. Also tell them when you are leaving so that they are not left talking to thin air after you have moved away. Use of the patients' names when you address them will also help to ensure that you do not startle them when speaking or touching. A squeeze of the fingers or arm is an excellent substitute for a smile and can be very reassuring in strange surroundings or when some treatment or change is being planned.

It is important that everyone who is likely to come into contact with visually handicapped patients should be made aware of their condition and problems. This should include all staff - cleaners, porters and volunteers as well as nurses and doctors. At meal times enquiries should be very specifically addressed to the patient. A vague query "Coffee?", "Soup?", "Cereal?" means nothing to people who do not know where the question is being directed. They may either ignore the query, not realising it is being addressed to them and thereby run the risk of being labelled confused or uncooperative, or they may suffer embarrassment when they discover they have been answering queries which were meant for other people.

The question of labelling beds to indicate that the occupant is visually handicapped can arouse strong feelings on the part of both sighted and blind people. The anti-labelling faction consider it is patronising. Perhaps this could be so in a ward where communications

are good, but it might be preferable to be labelled "visually handicapped" than to be labelled "confused" or "uncooperative" because communication is poor.

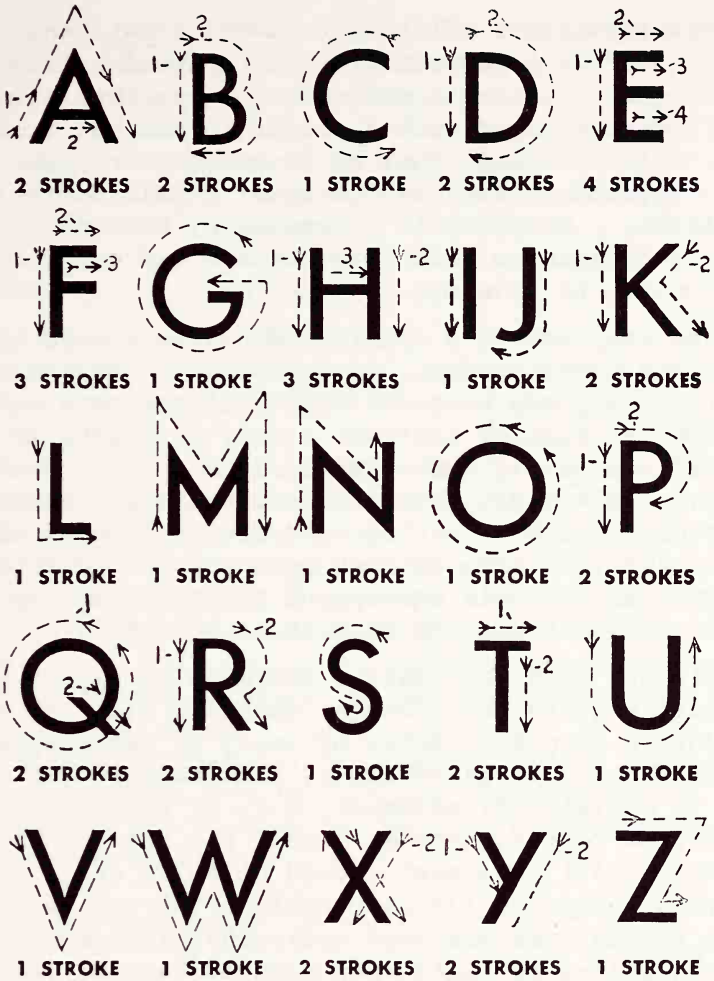
COMMUNICATION PROBLEMS OF THE SIGHTED

Many people become virtually tongue-tied when faced with a blind person because they think it will cause offence to use such words as "see" and "look". There is no need for any embarrassment on this score as blind people know what you mean. They would much prefer to be treated as normal human beings than to have the conversation edited for them.

Information about the patient's visual impairment may or may not be shown on his file. However, there is no reason why a patient cannot be asked what he can see. Answers such as "I can see you are there, but I can't see your face" or "I can see the light from the window" or "I can see the table by the door, but I can't see anything near me" will give some idea of his limitations. Whatever information is given on the file, it is a good idea to get the facts direct from the patient as every visually handicapped person has his own problems relating to his eye condition and his own reactions to those problems. For instance, variations in reactions to lighting levels and ability to distinguish colour contrasts can make it possible to see an object on one day and not to be able to see it at all on another. All too often a lack of understanding on these points leads to remarks such as "She can see when she wants to".

COMMUNICATION PROBLEMS OF THE DEAF/BLIND

There are particular communication problems relating to people who are both deaf and blind. It is essential that doctors and nurses have direct communication with them and this can be done by writing in block capitals on the palm of the patient's hand. The system is easy to learn and is illustrated as follows:-



The dotted lines indicate the DIRECTION and SEQUENCE of strokes to be made on the palm. Write as big as the hand will take and as slow as the recipient wants.

Most deaf-blind people are able to speak, but it may be necessary to listen very carefully to what is being said. Sheer nervousness may well be making it very hard for them to express what they mean. If no notice is taken, frustration or even despair can set in.

The importance of direct communication cannot be overstressed as interpretations by a third person could lead to quite erroneous diagnoses. Remember always how utterly isolated such a person is and how much he needs to be convinced that he is amongst friends. Try to avoid getting flustered or upset if misunderstandings arise. Patience is necessary by both parties to allow confidence to grow between them and any useful relationship to develop.

The approach to a deaf/blind person should be gentle and never sudden. Shocks to the nervous system are continuous because of lack of ordinary warnings provided by sight or hearing. Many outbursts of "temper" are simply the normal reaction to sudden shocks. Unless you have some unmistakable identification mark, such as a ring or a brooch, you should always give your name at each approach, or some agreed sign such as a double squeeze of the hand so that the patient knows at once to whom he is speaking.

Without sight or hearing there is no way of knowing what is going on in one's immediate vicinity and therefore a perpetual sense of worry is experienced. To lessen this, it is necessary that time should be taken to explain any movement, e.g. if the patient is required to move to another place, the reason should be given. All treatment should be fully explained to ensure the patient's cooperation. People who cannot see or hear are even more sensitive about intimate hospital routines than sighted hearing people. It is necessary to assure them positively that they can ask for what is needed and should not be shy. If not confined to bed the patient should be able to reach the toilet easily, he should know where all his personal possessions are and they should never be moved from place to place. The call bell should be accessible at all times.

FAMILIARISATION, ORIENTATION AND GUIDING

The patient should be helped to feel at ease, aware of his surroundings and capable of getting about as much as possible on his own.

Position of bed: The visually handicapped patient can be considerably helped by the choice of bed position. He will probably be more comfortable in a bed near a window with his back to the light so that he is not subject to the discomfort of glare. If he is near the toilets he will have more chance of finding his way there and back independently. Access to a power point will make it possible for him to use equipment such as special lighting or a tape recorder.

The occupants of the beds on either side and opposite the visually handicapped patient should be introduced to him and made aware of his sight problem. It is worth trying to ensure that his neighbours are less dependent than he is as it is usually possible to harness the goodwill of such patients for the benefit of the blind person. Problems of extreme frustration, which can delay recovery, can be caused by putting a blind person who has had a stroke and lost his power of speech in a situation where the other patients also cannot speak. If such a patient has neighbours who can converse and interpret noises and activities in the ward, much anxiety can be avoided. If it is possible it will be helpful for the patient to remain in the same position in the ward for the duration of his stay in hospital to save him having to reorientate himself once settled.

Making the most of residual vision: Helping the visually handicapped patient to keep his spectacles clean can literally shed a new light on his surroundings. "Eyes run on light" and any means of improving lighting can help patients to use their remaining vision. Even the most perfect eyes cannot function without the appropriate type of light and a sufficient amount of light.

The positioning of the light source is of the greatest importance. With some eye conditions problems are exaggerated by trying to read facing the light, for glare can be very painful. The light should fall over the shoulder and on to the equipment

or meal or anything else the patient is trying to see. The strength of the light is far less important than the distance away from the task. A 40 watt or 60 watt bulb in an adjustable light will be much more effective than a 200 watt bulb in a central ceiling fitting.

Keeping track of possessions: A patient's eye view of tidying up by hospital staff is summed up in this poem written by the late David Scott Blackhall:-

I took off my slippers right here by my chair -
When I want them again I shall know they are there
Which seemed quite a reasonably safe thing to say
'Til a nurse came and saw them and cleared them away.
Now nurses are trained to be tidy and neat
And that's why I'm walking about with bare feet.
If you move things six inches they might as well be
Where the mountains of Mourne sweep down to the sea.

Because they're called slippers they couldn't stay put
And it seemed quite appropriate to move them one foot.
My coffee was silently placed on my tray
But nobody thought it was worthwhile to say;
I ordered boiled eggs but got bacon instead;
Tomatoes were a bonus - and leathery bread -
And the eggs were so hard that I wanted to be
Where the mountains of Mourne sweep down to the sea.

(Broadcast on "In Touch" 1st September 1981 by the late David Scott Blackhall and used with his permission and that of the BBC.)

This poem illustrates graphically the importance of leaving things where the blind patient can find them. Moving articles around may cause a patient to knock over a water jug or tumbler in his efforts to find what he wants. The bell should be shown and fixed

firmly in one position and the bedside locker should not be moved around once it has been arranged to suit the patient. It is worth taking time to discuss with the patient where he wants to keep such things as his denture container, hearing aid, spectacles, magnifier, soap, towel, shaving gear and any other item which he might need to make life comfortable and to enable him to maintain the maximum possible amount of independence.

Meal times: As pointed out in David Scott Blackhall's poem, it is important that the patient should know what is going on at meal times. If you do not tell a blind patient that you have put a cup of tea beside him it may be ignored or knocked over. The patient needs to know what is on the plate and where it is before the meal starts. Playing "hunt the mystery object" at meal times usually requires more of a sense of adventure than a sick blind person can summon up. (Try eating a meal blindfolded without knowing what is on the plate yourself sometime!). A useful way to describe meals is to use the clock face - e.g. peas at two o'clock, mashed potatoes at six o'clock and fish at ten o'clock. Be sure you are describing the positions from the patient's viewpoint and ask if he needs help with cutting up any food or removing bones.

There are many other small ways in which life can be made more comfortable for visually handicapped patients. A heavy bottomed water bottle or tumbler is more difficult to knock over than a light one and for those with some sight the outline of a coloured glass or mug is easier to recognise than a transparent one. Colour contrasts - between the table and the plate and between the plate and the food - will help. Sometimes a coloured paper napkin on the tray can be used to provide the contrast which will make it easier to locate the plate. A large plate is better than a small one. Pudding served in a soup bowl with a spoon and fork will be more manageable than if it is served on a flat plate or a small dish. It is easier

to cope with a plain plate than to struggle to pick the pattern off a decorated plate with a fork.

Bottles, bedpans and loos: Instructions should be very carefully given as to how to get and use a bottle or bedpan. A blind man will probably find it reassuring to keep a bottle in bed with him. An escorted visit to the lavatory as soon as possible after admission will be helpful to ambulant patients. There are numerous methods of flushing lavatories - chains hanging from above, handles attached to walls, buttons set in floors and so on. A blind person needs to be shown the local variation and also to know where the lavatory paper can be found and to be reassured that there is actually paper on the roll. It can also be difficult for someone with poor vision to locate the end of a new roll of toiler paper and a bit of help will be appreciated if the roll has not been started already.

Guiding: Guiding a patient who can get about on foot to the toilet, bath or treatment can be a more comfortable experience for both guider and guided if staff take the trouble to learn some simple techniques. Wherever possible the maxim should be

If you want to help the blind
Lead from the front, don't push behind.

In addition do not push a blind person into a chair, put his hand on the back, arm or seat of the chair, allow him to feel around and to seat himself in his own time. It is most unnerving to be abandoned by a guide in strange surroundings, so keep in physical contact until the person you are guiding knows where he is or has been told where to stay and who will be dealing with him next. Remember that even the largest gesture accompanying words like "over there" is unlikely to communicate any useful information.

A comprehensive introduction to sighted guiding is given in the pamphlet *"How to guide a blind person"* obtainable free of charge (up to 50 copies) from the Royal National Institute for the Blind.

STIMULATION AND RECREATION

Some visually handicapped patients are happy to be left in peace, but others may become frustrated and bored because they cannot read newspapers or magazines or occupy themselves with such activities as assembling jigsaw puzzles. There are various ways in which these latter patients can be helped.

There is an "Illustrated Catalogue of Apparatus and Games" for the visually handicapped, together with the current price list, available free from the Royal National Institute for the Blind. People who are registered blind or registered partially sighted can buy items from the catalogue at concessionary prices. In some parts of the country the local voluntary association for the blind may be able to lend equipment for the use of hospital patients.

Writing aids: A writing frame used with a felt tip pen may help a blind person to correspond with friends or relatives. Signature guides for cheque books and pension books can encourage independence.

Watches and clocks with tactile markings are available from the R.N.I.B. Some people with residual vision find they can use a kitchen clock with bold figures. Talking clocks are now available commercially.

Games: There are many games which are adapted for the visually handicapped, e.g. chess, draughts, dominoes, Mastermind and various puzzles. Braillists can have Scrabble and playing cards with braille markings. There are also cards with moon markings (an embossed script based on the roman alphabet and named after Dr. William Moon). Large print playing cards can often be used by people with limited vision. All these games can be played with sighted patients, so reducing any sense of being left out in a ward or day room.

Telephone aids: There are large print self-adhesive dials obtainable from British Telecom (black on cream)

and also from some voluntary associations (white on black). If such a dial could be fitted to all telephone trolleys and in kiosks used by patients, it would be helpful to many people.

Radios and Talking Books: A blind person may be happier with his familiar radio or Talking Book than with the hospital equipment. To save disturbing other patients, earphones can be supplied by many of the local voluntary associations or direct from the Wireless for the Blind Fund. The same earphones can be adapted to fit a Talking Book machine by the use of a jack plug obtainable from the Talking Book Service for the Blind.

Talking Newspapers: These provide local news on standard cassettes and are produced in most parts of the country. Advice on availability should be sought from the local voluntary association. Many people subscribe to magazines and information tapes which are also recorded on standard cassettes. These can help to keep boredom at bay if the hospital is prepared to accommodate the necessary equipment.

Large print books from the hospital library can sometimes be enjoyed by people with residual vision and large print Bibles can be obtained on application to Gideons International.

RESOURCES

It would probably be helpful to all staff if one person in the hospital, perhaps an Occupational Therapist, a Social Worker, a Librarian or the Organiser of Volunteers could make herself responsible for knowing where aids and apparatus for the visually impaired are kept and who to contact nationally or locally for additional information and help.

A useful address list could include:-

Royal National Institute for the Blind
224 Great Portland Street, London W1N 6AA 01-388 1266

British Talking Book Service for the Blind
Mount Pleasant, Wembley, Middx. HAO 1RR 01-903 6666

British Wireless for the Blind Fund
226 Gt. Portland Street, London W1N 6AA 01-388 1266

Southern and Western Regional
Association for the Blind
55 Eton Avenue, London NW3 3ET 01-586 5655

North Regional Association for the Blind
Headingley Castle, Headingley Lane,
Leeds LS6 2DQ 0532 752666

Scottish National Federation for the Blind
8 St. Leonard's Bank, Perth, Scotland 0738 26969

Wales Council for the Blind
Oak House, 12 The Bulwarks,
Brecon, Powys, Wales 0874 4576

In Touch (programme)
BBC, Broadcasting House,
Portland Place, London, W.1. 01-580 4468

In Touch (publications)
35 Marylebone High Street,
London W1M 4AA 01-580 5577

National Deaf Blind Helpers League
Rainbow Court, Paston Ridings,
Peterborough, Cambs. PE4 6UP 0733 73511

Local Social Services Department (able to advise about specialists - such as Mobility or Technical Officers employed locally: probably best contacted through Hospital Social Workers).

Local Voluntary Association for the blind (address can be supplied by Southern and Western Regional Association for the Blind).

Local Talking Newspaper (contact via local Voluntary Association).

Gideons International,
Western House, George Street,
Lutterworth, Leicestershire LE17 4EE 045 55 4241

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Gideons International,
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Lutterworth, Leicestershire LE17 4EE 045 55 4241

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Training aids which can be borrowed from the Southern and Western Regional Association for the Blind or purchased direct from addresses below, are:-

(a) Slides

Camera Talks No. 344/Part 1. The Visually Handicapped. The slides cover ametropia, cataract, hemianopia, retinitis pigmentosa, macular degeneration, diabetic retinopathy and glaucoma.

Camera Talks,
31 North Row, London W1R 2BM 01-493 2761

Warwick Research Unit for the Blind. Visual Defects Simulations. These slides cover myopia, cataracts, macular degeneration, tunnel vision, diabetic retinopathy.

Warwick Research Unit for the Blind,
University of Warwick, Coventry CV4 7AL 0203 24011

(b) Simulating spectacles

Set of eight spectacles simulating the following eye conditions: Hemianopia in the lower section, macular degeneration, multiple sclerosis or retinitis pigmentosa, tunnel vision, bi-lateral hemianopia and three examples of acuity loss.

C. Davis Keeler Limited,
21-27 Marylebone Lane,
London W1M 6DS 01-935 8512

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